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ABSTRACT

Asserting that the "children's budget" expected from the Canadian federal government in February 2000 may fail to address the needs of children and youth with disabilities, this report argues that the federal government has a variety of avenues open for meeting these needs. The report contends that it is essential to ensure that families caring for children with disabilities receive financial assistance in recognition of their extra costs related to technical aids and equipment, specialized services, and respite care. The report further discusses ways for the federal government to invest in services, focusing on improving services to ensure that all services for children are accessible; and expanding services through the use of a national child development fund to invest federal money in provincial services. Maintaining that existing tax provisions tend to have an institutional bias toward care and are restrictive and exclusionary in their provision, the report notes several changes that can make the income tax system more responsive to the needs of families of children with disabilities, including enhancing the disability tax credit and the medical expense tax credit and introducing a new disability credit. The report notes that the children's budget should take steps to simplify and clarify existing tax provisions. (Contains 17 references.) (KB)

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Will the 'Children's Budget' Include Kids With Disabilities?

by

Sherri Torjman

November 1999

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What's the problem?

There could be a serious omission in the so-called 'children's budget' that Ottawa is expected to bring down in February 2000. It may fail to address the needs of a large number of Canada's children – the 458,000 children between the ages of 0 and 11 and the 304,000 young people between the ages of 12 and 19 with some form of disability. They could be excluded from any measures intended to help families with children – just as they are still left out of the mainstream of everyday life in classrooms, libraries, sports complexes, community centres, theatres, and other public and private facilities.

Because of their myriad and complex requirements, children with disabilities and their families typically are overlooked by the federal government. They remain a publicly invisible group with little political clout. There are additional reasons for Ottawa's myopia regarding children with disabilities. For one thing, their needs are seen as largely 'provincial.'

Education, health and social services fall primarily within provincial jurisdiction. Ottawa used to play an important role in provincial social policy: Under the now-defunct Canada Assistance Plan, the federal government shared half the cost of welfare and approved social services, and had some (albeit limited) say in their delivery.

The federal financial contribution now takes the form of a single, multipurpose 'block fund' under the Canada Health and Social Transfer (CHST). Block funds translate into a hands-off, it's-not-your-business-how-we-spend-it form of financing in which Ottawa has virtually no control over how provinces use their federal money. In reality, the provinces can spend their CHST funds any way they want, including on areas outside of social policy.

There is hope that the new Social Union Framework Agreement will smooth some of the friction that has chafed federal-provincial relations in recent years. The National Child Benefit has proved that significant progress is possible when both levels of government work together to achieve a common goal.

Moreover, in October 1998 the federal and provincial governments (except Quebec) jointly signed a vision document entitled *In Unison* in which they agreed to pursue a collective agenda to achieve full citizenship for Canadians with disabilities. The vision of full citizenship is to be attained through three large building blocks: disability supports, employment and income security.

The author gratefully acknowledges the comments of Harry Beatty, Director of Policy and Research, Advocacy Resource Centre for the Handicapped (ARCH).

But will these achievements lead to substantive improvements for families caring for children with disabilities? Will the upcoming federal budget provide some support for needs that are complex, disparate and deemed to be primarily 'provincial'?

There are basically three kinds of supports that children with disabilities may require: 1) technical aids and equipment, 2) specialized services, and 3) respite care for families to provide some relief from their caregiving responsibilities.

Many children with disabilities need some form of equipment or technical aid (e.g., a wheelchair or hearing device) to assist them in the activities of daily living, such as mobility and communication. They also may require special educational materials or equipment, such as textbooks in alternate formats (e.g., tape, large print or Braille) or wide computer screens and special software. These aids may be provided directly through specific programs or indirectly through income tax measures (described below) that help eligible households offset these costs.

Second, children with disabilities may require various services to assist with daily living, with health-related conditions or with communication and learning problems. A child may need regular monitoring, for example, to stabilize a medical condition.

Specialized services often involve some form of certification or accreditation on the part of the provider. These services typically are delivered through a hospital- , health- or community-based program that controls their quality and delivery. Sometimes parents have to pay out of pocket for these services; parents may be eligible for certain income tax breaks to help offset these expenses. Some specialized services for children, such as those that assist with communication or learning, may be provided at school at no charge.

Finally, parents themselves often require assistance in the form of respite care – i.e., temporary relief from their caregiving responsibilities [Torjman 1997]. Respite care may be provided through services delivered by a program available in the community. Typically, however, respite care is purchased privately by families (if they can afford it).

But the availability and provision of these supports and services for families with children who are disabled vary widely among and within provinces. The difficulties are particularly acute with respect to specialized services, of which there is a serious shortage – both at home and in schools and other community settings. Respite care, in particular, should qualify under the proposed federal legislation for endangered species – except for the fact that it hardly existed in the first place: There is virtually nothing to protect.

There are three main streams of action that Ottawa can take in the coming 'children's budget' to provide more assistance to families with children who are disabled: 1) direct provision of services, 2) offsetting the cost of service purchase, and 3) a combination of these two approaches. The first route involves the improvement and expansion of services. The second option entails offsetting part of the cost of disability to families through the direct provision of cash benefits or through enhanced tax assistance. The third possibility is to introduce some combination of service provision and compensation for costs.

Investing in services

i. improving services

The first step in any children's agenda is to ensure that the existing network of services allows participation by children with disabilities. All governments made a commitment to breathe life into the principle of citizenship when they signed the *In Unison* vision paper.

The objective of full citizenship as stated in the *In Unison* document is to make as inclusive as possible all domains of Canadian society. Full inclusion means that public spaces, facilities and programs are accessible to the entire community, including persons with disabilities.

In the context of the children's agenda, generic programs intended explicitly for children must be accessible to all children, including those with a disability. These resources involve schools, child care centres, children's health services, child welfare services and recreational facilities. 'Accessible' refers to more than just physical access. It means that children can avail themselves of the range of programs and services in these facilities regardless of whether they have a physical, communication, mental or learning disability. Such programs and facilities should be able to accommodate each child's specific disability through the provision of a wide range of specialized aids and services as required.

At the very least, any new funds for children's initiatives should come with an accessibility standard. New funds for early childhood development programs, for example, should be made available only to preschools or programs that meet accessibility standards and whose staff are prepared to accommodate children with a disability.

In cases where the facility is unable to meet the special needs of a given child (e.g., the needs may be highly complex), funds should be provided to enable the program to obtain the required supports. Alternatively or in addition, parents should be able to make a tax claim to help defray part of these costs.

In short, the first step in the disability agenda is to design and upgrade all public space, facilities and programs to be accessible to all citizens, including children with disabilities. A supplementary measure is to provide assistance, possibly through tax measures, to ease the burden of the extra costs that parents must incur when public facilities and programs do not accommodate the specific needs of their child.

In addition to ensuring accessibility, the benchmarks for success of existing programs must be changed. The federal document that sets out the National Children's Agenda, for example, identifies a series of benchmarks for 'healthy' child development in the areas of physical well-being, learning readiness, social engagement and competence. These so-called 'outcomes' or standards for 'desirable' development exclude many children with disabilities who may not follow the generalized norm with respect to their development. But their unique developmental paths should be recognized and supported.[1]

ii. expanding services

The existing network of services for families – and the provisions for measuring and assessing their performance – not only must be *improved*. The network also must be *expanded* because it is inadequate to meet the wide range of diverse needs of children with disabilities.

One way to augment the network of services is through a national child development fund that invests federal money in provincial services. Caledon has proposed such a fund, respecting the provisions of the Social Union Framework Agreement and using the National Child Benefit as a model [Battle and Torjman 1999].

Through the reinvestment agreement of the National Child Benefit, the federal government is financially helping the provinces and territories invest in a range of child-related initiatives for low-income families that include services such as child care, early childhood development and supplementary health provisions (e.g., dental care). Ottawa can use this successful process as a model for establishing a national child development fund to help finance a range of child and family initiatives on a sustained basis.

Under our proposal, Ottawa would invest a sum of money in respect of child development services. We define the latter broadly to cover a continuum of supports that include prenatal care, parenting programs, early childhood stimulation, nursery programs, family resource centres, child care and respite services for parents.

The federal government would negotiate with the provinces to encourage them to devote additional spending in this area, to augment the new federal money. In order to ensure adequate investment as well as stability in the financing arrangement, the child development fund should set out a five-year schedule of funding that would be renewed twice a decade in future.

Ideally, the federal money would lever new and additional provincial investment in early childhood development. But our proposed national child development fund also would expect communities, foundations and employers to contribute money and other resources for this purpose (e.g., space, equipment, vehicles, books, toys and computers).

A child development fund would be broad in scope and would be intended to provide supports for all families with children, regardless of income. Following the practice of the National Child Benefit, provinces would be required to report detailed financial and program information on their use of the child development fund.

The *National Child Benefit Progress Report: 1999* notes that a key purpose of future National Child Benefit (NCB) reports will be to monitor program activities and the results they generate, and to present research and evaluation results that will indicate whether the initiative's goals are being met. The report points out that monitoring is essential to ensure accountability to the public for funds invested in the NCB. "Federal, provincial and territorial governments are committed to reporting on and evaluation of the National Child Benefit, particularly since its program activities are still evolving" [National Child Benefit 1999: 25].

In respect of the commitment made by Ottawa and the provinces under the *In Unison* agreement, the needs of children with disabilities and their families would be identified explicitly as a priority concern of the child development fund. Funds could be directed towards ensuring the accessibility of early childhood education and child care programs, as well as providing help at home for children with severe disabilities and respite care for families. (Respite services should be available for all families, including households whose children have a disability.) The proposed national child development fund also could be used by provinces for special assistance and individualized support to help children with disabilities par-

ticipate in integrated classrooms in community schools.

Negotiating a national child development fund will take time. In the meantime, the federal government can support disability-specific demonstration projects that promote inclusion in the mainstream of society. Funding could be provided, for example, for an 'extend-a-family' program that matches two families with children of a similar age; one family has a child with a disability. This approach would help ensure that both families have a source of respite.

The real challenge of the National Children's Agenda is to build the supply of quality services available to all families, including parents whose children have a disability. When it comes to specialized supports, helping parents pay for services is important – but is not a complete answer. If children require assistance that involves trained and certified staff, it is not simply a question of giving parents enough money or allowing them to deduct the costs in order to facilitate the purchase of these services.

There must be sufficient and appropriate services to purchase. An investment of funds in the supply of supports and services for families with children who are disabled is crucial.

But as in the case of anything political – and especially anything federal/provincial – such an arrangement could take some time to negotiate, and more time to implement. Many more years likely would pass before there were any semblance of an adequate range of family-related supports and services in place throughout the country.

In the meantime, all too many Canadian families need some support and relief right now. What can the so-called 'children's budget' do to help them?

Offsetting disability costs

There are several possible actions that Ottawa could take in the coming 'children's budget' to provide more assistance to families with children who are disabled. In theory, it is possible to expand the National Child Benefit to include an additional amount for these families. The money would be used to help offset the extra costs of equipment and services associated with a disability.

But the National Child Benefit is not the appropriate instrument to help children with disabilities. There are several reasons why.

Delivery is a major problem. Ottawa's part of the National Child Benefit, the Canada Child Tax Benefit, is a geared-to-income program that serves low- , modest- and middle-income families with children. Payments are based on level of net family income, as determined by the income tax system. Maximum benefits go to lower-income families, with payments to non-poor families that diminish as incomes rise.

This delivery mechanism represents a key strength of the Canada Child Tax Benefit. The fact that it is 'income-tested' means that there are no intrusive 'needs tests,' notably those administered by welfare departments, to ascertain the eligibility of a given household and the amount of assistance it receives.

Needs tests involve an exhaustive, intrusive and labour-intensive investigation of families needs and resources, taking into account such factors as income, fixed and liquid assets,

deemed employability of adults and family characteristics. By contrast, the Canada Child Tax Benefit employs a simple measure – net family income, which is already calculated in the annual income tax return – to determine both eligibility for and amount of benefit.

The income tax system has some strong advantages as a vehicle for delivering income security benefits. It is administratively efficient, covering virtually all Canadian households. It brings none of the stigma associated with needs-tested welfare. It automatically determines eligibility for social benefits, such as the Canada Child Tax Benefit and refundable GST credit. It also delivers provincial refundable tax credits, including income-tested child benefits. (Quebec, which operates its own income tax system, also uses it to deliver income benefits.)

But an income-tested program administered through the tax system is not the best way to provide assistance to households with special needs. It is particularly inappropriate for parents whose children have serious health- or disability-related conditions.

Special needs vary considerably. They include, for example, modest expenditures for corrective eyeglasses, orthopedic shoes and hearing aids. But they also can comprise expensive items such as special communications equipment; substantial modifications to home, furniture, equipment and vehicles; and attendants to provide specialized forms of care. It would be impossible to assess eligibility for this assistance or extent of need without a special test that would require certification by designated professionals.

Such certification through the income tax system is possible. In fact, eligibility for the disability tax credit, described below, requires the completion of a standard form by a physician, optometrist or audiologist. (Occupational therapists may now complete the portion of the form pertaining to dressing and feeding oneself and to walking. Psychologists may complete the portion of the form regarding a person's ability to perceive, think and remember.) Taxfilers cannot qualify for the disability tax credit without this form.

So a needs-tested dimension could be grafted onto the Canada Child Tax Benefit. But this is not desirable. The Canada Child Tax Benefit is neither intended nor able effectively to compensate for the additional costs of special needs. These costs would be more appropriately offset in a number of ways through various provisions in the income tax system.

It is possible to extend the age of eligibility for the Canada Child Tax Benefit – say up to age 25 for children with disabilities who remain dependent on their parents. This extension would provide some financial relief for these families, but again would not respond to the specific disability-related costs that households incur.

i. medical expense tax credit

The medical expense tax credit helps offset the cost of a designated list of health-related goods and services, and disability supports. The credit may be claimed in respect of the medical expenses of a taxfiler, spouse or dependants. Its provisions apply to all Canadians and not just to persons with disabilities.

Total medical expenses must be more than $1,614 or three percent of net income, which-

Summary of Disability Tax Provisions

	purpose	eligibility	benefit formula	federal-average provincial tax savings in 1999	total federal-average provincial expenditures in 1999
medical expense tax credit	to help offset the cost of designated health-related goods and services	total medical expenses must be more than $1,614 or 3 percent of net income, whichever is less; expenses must meet list of eligible goods	existing credit is supplemented by a refundable tax credit for low-income employed Canadians with high medical expenses; taxfilers must earn at least $2,000 to qualify for this portion; credit is reduced by 5 percent of net family income in excess of $16,069	average $416 ($277 federal; $139 average provincial) in 1996 (the latest date for which data are available)	$585 million ($390 million federal; $195 million average provincial); $40 million federal for the medical expense supplement for the working poor
disability tax credit	to help offset the actual and hidden costs of disability	disability that is severe and prolonged which markedly restricts the activities of daily living	parents can apply the unused portion of the disability credit to reduce their own federal and provincial income taxes	maximum $1,080 ($720 federal; $360 average provincial)	$413 million ($275 million federal; $138 million average provincial)
infirm dependant tax credit	to help recognize the contribution of caregivers of infirm dependants over age 18	dependant must be age 18 or over and must be reliant upon the taxpayer by reason of mental or physical infirmity	credit is reduced by 17 percent of dependant's net income over $4,103, including workers' compensation, the Guaranteed Income Supplement and welfare	maximum $600 ($400 federal; $200 average provincial)	$11 million ($7 million federal; $4 million average provincial)
caregiver tax credit	to help recognize the contribution of caregivers of infirm dependants over age 18 and of dependants over 65 who reside with the taxpayer	dependant must be age 18 or over and must be reliant upon the taxpayer by reason of mental or physical infirmity, except for dependants over age 65	credit is reduced by 17 cents for every dollar of the dependant's net income above $11,500; eligibility ends once dependant's net income reaches $13,853	maximum $600 ($400 federal; $200 average provincial)	$188 million ($125 million federal; $63 million average provincial)
child care expense deduction	to help offset the cost of nonparental child care	deduction must be claimed by parent with the lower income; receipts are required for the provided child care	maximum $7,000 for each eligible child aged 0-6; $4,000 for each eligible child aged 7-16; if child is eligible for disability tax credit, maximum $7,000 up to age 16; up to $4,000 regardless of age for children who do not qualify for disability tax credit but who are mentally or physically infirm	for children under 7: maximum $1,785 for taxable income under $29,590; $2,730 for taxable income between $29,591 and $59,180; $3,045 for taxable income over $59,180; for children 7-16: $1,020 for taxable income under $29,590; $1,560 for taxable income between $29,591 and $59,180; $1,740 for taxable income over $59,180	$855 million ($570 million federal; $285 million average provincial)

ever is less. The expenses deemed eligible for the credit include (but are not limited to):

- payments to medical practitioners, nurses and hospital services
- attendant care
- registered nursing services, including home care
- care at a school or institution where special care and training is provided
- ambulance services
- personal transportation for medical care (trips over 40 km.)
- travel costs of an attendant
- medical devices (e.g., artificial limbs, wheelchairs, braces, eyeglasses and a list of prescribed devices)
- expenses for guide (seeing-eye) and hearing-ear dogs
- expenses related to bone marrow and organ transplants
- home modifications for accessibility
- rehabilitation therapy
- prescribed drugs
- diagnostic services
- dental services
- contributions to private health services plans.

The medical expense tax credit is deducted from basic federal income tax. Because all provinces except Quebec base their income taxes on the federal income tax, the medical expense tax credit and the numerous other nonrefundable tax credits reduce provincial as well as federal income taxes. The average federal income tax savings from the medical expense tax credit was $277 in 1996, the most recent year for which data are available. The average provincial income tax savings was $139, for a total federal/average provincial tax savings of $416 in that year.

The 1997 federal Budget enhanced the medical expense tax credit. Prior to that time, the credit was nonrefundable. This means that the credit reduced income taxes owing but did not benefit Canadians with incomes below the taxpaying threshold. The medical expense credit was therefore of little or no assistance to very poor households.

The 1997 Budget rectified this problem somewhat by making the credit partially refundable. The existing medical expense tax credit is now supplemented by a refundable tax credit for low-income employed Canadians with high medical expenses. The maximum credit is the lesser of $500 and 25 percent of eligible medical expenses. Taxfilers must earn at least $2,000 to qualify for this refundable portion. The credit is reduced by five percent of net family income in excess of $16,069.

While this change is a step in the right direction, it has some serious limitations. The eligibility conditions for the medical expense tax credit are restrictive. Moreover, low-income earners typically cannot pay up front for medical expenses, even if they are reimbursed later (though not necessarily for the full cost).

In 1999, the federal government will spend a projected $390 million in respect of the medical expense tax credit. The provincial cost

is an estimated $195 million, for a total federal/provincial estimated cost of $585 million. This figure represents the total cost of medical expenses claimed by all Canadians, not just the amount for disability-related goods and services.

In 1999, the medical expense supplement for the working poor will come to a projected $40 million in federal expenditure only. The combined federal/provincial total for both the regular medical expense tax credit and the medical expense supplement for the working poor will amount to an estimated $625 million in 1999.

The medical expense tax credit could be enhanced in respect of children with disabilities in several ways. While the credit currently comprises a long list of allowable expenses, there are many areas not covered. The cost of nutritional supplements, for example, is not included even though these are essential for individuals with special dietary needs.

Some possible claims are uncertain. While the cost of special schools may be deducted, it is unclear whether the fees incurred for certain schools qualify if medical or health-related assistance is not provided on site [Beatty 1999: 97]. It is likely that fees for schools which assist children with disabilities on a segregated basis would qualify. By contrast, assistance provided to a child with a disability within an integrated educational setting is less likely to be eligible as a medical expense.

This distinction tends to reinforce the institutional – and indeed segregationist – bias inherent in the medical expense tax credit. Parents effectively have no choice but to use this tax provision because there are no other measures that allow claims for special educational fees.

The credit also could be modified to provide greater recognition for family care. As it stands, the medical expense tax credit is very much recognition of just that – medical expenses incurred for care delivered by professionals primarily outside the home.

Yet many families with a child who is disabled provide hours of care – often around-the-clock – to their child at home. Ironically, the cost of this child's care would be paid for fully or at least partially by governments if the parents were to place the child in a home or institution – an unacceptable and inappropriate solution in most cases.

There have been some minor enhancements to the medical expense tax credit in the past few years. The 1998 Budget announced that a medical expense claim may be made for the amount paid for a taxfiler, or a relative of the taxfiler, to learn to care for an individual who is mentally or physically infirm. The infirm individual must live in the taxpayer's household or depend on the taxpayer for support.

The 1999 Budget allowed a medical expense claim for the payments to individuals providing care and supervision in a group home for persons with severe physical and mental disabilities who are eligible for the disability tax credit (described below). This is an admittedly small but welcome measure.

The change does nothing, however, to provide additional assistance to families looking after their children at home, again reinforcing the institutional bias of the medical expense tax credit. The allowable costs under the new pro-

visions must be incurred primarily for medical, institutional and professional forms of care.

Ottawa also could increase the value of the medical expense credit. For example, it could raise the current limit of 17 percent of eligible medical expenses over three percent of net income. The three percent limit on net income could be reduced or eliminated.

Yet improvements to the medical expense tax credit, while essential in themselves, still confer the greatest benefit to taxpayers with higher incomes who tend to claim higher medical costs. One option is to target the improvements to individuals and families with disabilities and major health problems. For example, the measures could be limited to those who qualify for the disability tax credit, described below. The problem is that the latter credit excludes many persons with disabilities who fail to meet the restrictive eligibility requirements. And denying improvements to taxpayers not classed as having a disability could be seen as unfair.

Alternatively, the refundable portion of the credit could be enhanced to target additional assistance on lower-paid families. For example, the level at which the reduction in the claim begins – $16,069 – could be raised, say to $20,000, to allow more claimants to receive the maximum value of the refundable portion and to raise the income level where eligibility for partial benefits ends.

Another option is to extend the refundability of the medical expense tax credit to those who qualify for the disability tax credit. While either or both of these enhancements would help offset costs, they would not solve the more basic problem of the narrow list of eligible expenses.

ii. disability tax credit

Another way to help families with children who are disabled is to enhance the disability tax credit. The disability tax credit provides modest tax relief for the additional – but often hidden and indirect – costs of disability. In contrast to the medical expense tax credit, the disability tax credit does not impose a list of allowable expenses. The hidden costs of disability include, for example, higher utility costs, additional transportation costs, higher prices for goods because of fewer shopping choices and reduced capacity to earn income.

There are also many hidden costs related directly to the care of children. A child with a disability may require, for example, a trained caregiver rather than a babysitter. The child with a disability may need a caregiver or babysitter even at an age when a child typically would not require such supervision. Other hidden costs include dietary supplements, special toys, adapted equipment, tailor-made clothing or other items, such as diapers.

In order to qualify for the disability tax credit, claimants must have a physical or mental disability that is severe and prolonged which markedly restricts their ability to perform one or more activities of daily living all or almost all of the time. 'Prolonged' means that the impairment has lasted or may be expected to last for a continuous period of at least 12 months. 'Severe' and 'markedly restricted' mean that all or almost all of the time the person is unable, or requires an inordinate amount of time, to perform a basic activity of daily living, even with therapy and the use of appropriate devices and medication.

The specific diagnosis or condition is irrelevant. What is important is the impact of

that condition upon the person's ability to carry out one or more basic activities of daily living. These include feeding and dressing oneself; eliminating (bladder or bowel functions); walking; perceiving, thinking and remembering; and speaking so as to be understood in a quiet setting, by another person familiar with the individual. Problems have arisen, however, with respect to the interpretation of these provisions (described below).

In 1999, the disability tax credit is worth a maximum $720 or $1,080 in combined federal/average provincial tax savings. In 1999, the disability tax credit is expected to cost $275 million in foregone federal tax revenues and an estimated $138 million in foregone provincial revenues, for a combined federal/provincial total of $413 million.

The fact that the disability tax credit is nonrefundable means that it is of no value to persons too poor to pay income tax. However, in cases where an individual pays no income tax or not enough to benefit from the entire credit, the unused portion can be transferred to another family member.

Parents can apply the unused portion of the disability credit to reduce their own federal and provincial income taxes. But many parents are unaware of this provision. And the tax guide's explanations are virtually incomprehensible.

An equally serious problem arises from the fact that, even if the rules were readily understandable, they have become increasingly restrictive in recent years – the result of both legislative amendment and more narrow administrative interpretation [Beatty 1999]. A 1991 legislative amendment toughened the provisions of the disability tax credit by setting out the specifications for 'severe' and 'prolonged' impairment. The list narrowed the range and severity of qualifying conditions.

It is not uncommon for an impairment to be severe and prolonged but not necessarily continuous. Some disabilities are progressively degenerative. Still other conditions involve periods of remission – which means that a given individual may have certain times of normal activity followed by bouts of inability to function. But the rules now require that the impairment be continuous for at least 12 months, effectively eliminating many individuals with severe and prolonged disabilities that happen to manifest themselves episodically or intermittently rather than chronically.

Worse, an episodic or degenerative condition is often more difficult for families to cope with than one which is severe and prolonged with no periods of improved functionality. Disability income and service programs are set up as though the world were black and white – a person either has the condition or not, an individual qualifies or does not. There is no recognition of the reality that disability typically is far more 'gray' and complex than the rules acknowledge or allow.

The disability tax credit certificate formerly permitted health professionals to list other disabling impairments that would justify qualification for the credit. That section has been removed [Beatty 1999: 57-59]. The bottom line is that parents may not be able to claim any disability tax credit in respect of their child. They also may not qualify under the other tax breaks, described below, which have built-in age restrictions on the definition of 'dependant.'

There should be a full review of the eligibility provisions of the disability tax credit. The

review should involve members of the disability community and other key stakeholders so that adults and children with disabilities no longer are disqualified from this tax provision on questionable grounds.

It is essential to resolve the eligibility problems around the disability tax credit – not just to ensure access to the credit. Eligibility for other tax provisions, such as the deduction for attendant care and the extended provisions of the child care expense deduction (discussed below), are contingent upon eligibility for the disability tax credit.

Finally, there is no financial assistance provided for the completion of the disability tax credit certificate. Low-income households may not be able to afford to pay health professionals for this service.

In short, the disability tax credit could be improved in one of three ways: relaxing the eligibility criteria, enhancing its value (both in amount and relative to the cost of living) and making it refundable.

The credit should not employ a definition of disability that is so restrictive as to keep out a significant population that could qualify for such assistance. The activities of daily living could be broadened to include other areas, such as working or housekeeping. Persons excluded by the existing eligibility criteria may not have limitations as narrow, severe and prolonged as those required by the current credit but they nonetheless incur substantial costs as a result of a disabling condition.

A more generous disability tax credit would continue to allow a flat-rate claim in respect of the actual and hidden costs of disability. However, the amount would be greater than that currently permitted.

Another crucial improvement would be to index the value of the disability tax credit fully to inflation. There have been no fully-pegged-to-inflation increases for any tax credits since the income tax system was partially deindexed in 1986. Adjustments are limited to the amount of inflation over three percent, which means that credits are frozen when inflation is less than three percent and only partly increased when inflation exceeds three percent [Battle 1998].

Partial deindexation refers to the fact that tax credits have declined steadily in value over time relative to the cost of living. The result is an annual reduction in the value of all tax credits and an associated hidden increase in the federal and provincial income tax burden for taxpayers at all income levels, but especially for low-income households [Battle and Torjman 1999]. The partial deindexation of tax brackets has pushed about one taxpayer in five into a higher tax bracket, adding to their rising tax burden.

Finally, the introduction of a refundable component would help recognize that many households which incur disability-related costs have low incomes. This problem may be due to persons with disabilities' limited ability to work or, in the case of parents of a child with a disability, to the fact that it may not be possible to have a two-earner household. Even if there are two earners, both parents often work less-than-full-time jobs to ensure that at least one parent is always home to provide care for the child with a disability.

Alternatively, Ottawa could consider introducing a new refundable disability tax credit. It would integrate the current disability tax credit with relevant disability provisions from the other key tax measures (i.e., the medical expense tax credit, infirm dependant tax credit, caregiver tax

credit and child care expense deduction). The one exception to total integration would be to allow individuals with extraordinary out-of-pocket disability costs which exceed a designated amount to continue to claim these costs as a medical expense. The proposed integration would help minimize the confusion with respect to the complex interplay of the existing provisions.

iii. infirm dependant tax credit

Another option for the upcoming 'children's budget' is to amend the infirm dependant credit. The dependant must be age 18 or older. While the tax provisions provide no clear guidance as to the meaning of 'infirm,' the credit may be claimed in respect of dependants with physical or mental disabilities. The lack of standard eligibility criteria and information about the credit means that there is no consistency in who claims the credit and in the determination of eligibility.

The infirm dependant tax credit lowers the federal income tax of the supporting individual by up to $400 and the provincial component by an average $200, for a combined maximum federal/average provincial tax savings of $600. The credit is reduced by 17 percent of the dependant's net income over $4,103, including workers' compensation, the Guaranteed Income Supplement and welfare. Eligibility ends once the dependant's net income exceeds $13,853.

In 1999, the infirm dependant tax credit will cost Ottawa a projected $7 million. The provincial portion is about $4 million, for an estimated federal-provincial cost of $11 million in that year.

The infirm dependant tax credit could be amended in two ways to better meet the needs of families with children who are disabled. First, the amount of the credit could be increased and it could be fully indexed to keep pace with the cost of living.

Second, and perhaps more important at this stage than an increase in the value of the credit, would be its extension to dependants under age 18. Because there are an estimated 750,000 children who potentially could fall into this category, an extension of the credit down the age scale would have to proceed gradually. This extension could provide an alternative to claiming children under the disability tax credit.

In the past, the Finance Department has objected to proposals to extend the infirm dependant tax credit to younger dependants on the grounds that families with children up to age 18 are eligible for assistance under the National Child Benefit. This argument holds no weight. The National Child Benefit was designed as a means to supplement the incomes of families with children. It never was intended as a way to recognize the extra and often hidden costs of disability.

Finally, the infirm dependant tax credit could be made refundable. This expansion would help poor households with children who are disabled. A major contributing factor to the low-income status of families whose children have severe disabilities is that a parent – usually the mother – is unable to work because of caregiving responsibilities. Single-parent households are particularly vulnerable in this regard.

iv. caregiver tax credit

As of the 1998 taxation year, a caregiver tax credit may be claimed by taxpayers who maintain a dwelling, either alone or with another

person, in which an adult dependant lives. The credit is intended to provide some support for family caregivers.

The caregiver tax credit reduces federal income tax by up to $400, for a maximum combined federal/average provincial tax savings of $600. The amount of the credit is reduced by 17 cents for every dollar of the dependant's net income above $11,500, which means that eligibility ends once the dependant's net income reaches $13,853.

The dependant must have been born in 1980 or earlier. The dependant must be reliant upon the taxpayer by reason of mental or physical infirmity, except for the taxpayer's parents and grandparents over 65 for whom evidence of infirmity is not required [Beatty 1999: 47].

But like the credit for infirm dependants, the caregiver tax credit requires that the dependant be older than 18. Again, there is no assistance or relief for families whose children are under 18 – aside from claiming an amount in respect of the disability tax credit *if* the disability is severe and prolonged, as earlier described.

It should be noted that the caregiver tax credit cannot be claimed by a taxpayer who is filing an amount for infirm dependants. The taxfiler basically has to make a decision as to whether to claim the caregiver credit or the amount for infirm dependants.

There are variations between the two credits that determine differences in eligibility. The dependant's income may be too high, for example, to make a claim for infirm dependants. If the taxfiler is eligible for both claims, it is advantageous to take the caregiver amount which is reduced less by the dependant's net income than is the credit for infirm dependants. If, however, the dependant's net income is low enough not to affect the infirm dependant credit, then either tax credit can be claimed [Beatty 1999: 80].

This short clarification is anything but clear. The General Income Tax and Benefit Guide should explain far more simply the difference between these two credits – as well as eligibility for other possible measures – so that taxfilers can better understand the provisions for which they are potentially eligible. It should not be necessary for households to require a chartered accountant or tax lawyer because they happen to have a family member with a disability.

Finally, as in the case of the infirm dependant tax credit, the caregiver tax credit should be made refundable. This is one way to provide some assistance to low-income households that derive little or no benefit from a nonrefundable credit.

v. child care expense deduction

Another option for the 'children's budget' is to enhance the value of the child care expense deduction for parents caring for children with severe disabilities.

The maximum child care expense deduction for children without disabilities is $7,000 for each eligible child aged 0-6 and $4,000 for each eligible child aged 7-16. The child care expense deduction must be claimed by the parent with the lower income. Taxfilers must produce receipts for the provided child care.

The maximum deduction of $7,000 for each eligible child under age 7 translates into a combined federal/average provincial tax savings

of $1,785 for claimants with taxable income under $29,590; $2,730 for taxfilers with taxable income between $29,591 and $59,180; and $3,045 for claimants with taxable income over $59,180.

The $4,000 deduction for older children provides a combined federal/average provincial tax savings of $1,020 for taxpayers with taxable income under $29,590; $1,560 for those between $29,591 and $59,180; and $1,740 for taxpayers with taxable income over $59,180.

However, parents whose children have severe disabilities and are eligible for the disability tax credit can claim up to $7,000 in child care expenses regardless of the child's age. In effect, the child care expense deduction has been enhanced for these families in respect of their children aged 7 to 16.

In addition, up to $4,000 can be claimed in child care expenses for a child who does not qualify for the disability tax credit but who is considered mentally or physically 'infirm.' No precise definition of this term is provided. The claim may be made regardless of the child's age. Not imposing an age limit is intended to recognize the fact that many families care for an adult child who is disabled.

Given the serious lack of community supports for children with disabilities, the very least that Ottawa could do is make more flexible its tax provisions to recognize the need for extra help. All parents require physical respite and emotional relief. But parents who care for a child with some form of disability face obvious and additional stresses. In recognition of this need, the federal government could allow a certain portion of child care costs to be claimed without producing receipts for children with disabilities.

Ironically, as noted, if parents are so exhausted or overwhelmed by their circumstances that they decide to place their child in a residential facility, this placement is financed fully or almost entirely by government. Yet extra assistance in respect of community and at-home care is not considered an acceptable expenditure.

There are inherent limitations, however, to the child care expense deduction as an instrument of relief for parents who have a child with a disability. First, the deduction recognizes only the cost of child care (i.e., care not provided by parents). It is intended primarily to help working parents pay for child care, not as a type of respite program. The deduction affords no assistance for the other goods and services associated with a health- or disability-related condition.

Another option is to allow the higher-income parent to make the claim for disability-related care needs, including respite services. This amendment would recognize that the child care responsibilities of mothers who stay at home to look after children with disabilities go beyond the ordinary caregiving responsibilities of all families. It would afford a higher level of tax relief than currently allowed under the medical expense tax credit.

vi. clear guidelines

Finally, if it does nothing else, the federal government should clarify eligibility for existing tax provisions. Many of the provisions are worded so unclearly and cross-referenced in a manner so complex as to be almost incomprehensible.

Line 318 of the General Income Tax and Benefit Guide, for example, states that the unused portion of the disability tax credit may be transferred from a dependant other than a spouse if one of five possible conditions apply. The second condition reads as follows: "The dependant was your or your spouse's child, grandchild, parent or grandparent and you could have claimed an equivalent-to-spouse amount on line 305 for that dependant if you did not have a spouse and if the dependant did not have any income."

By virtue of the fact that the two parts of this phrase are joined, it appears that the household must have a dependant *and* that the household had to be in a position to claim the equivalent-to-married credit (which is payable on behalf of one child in single-parent families) on line 305 of the General Income Tax and Benefit Guide. The wording of this condition implies that only single-parent families are eligible to claim the unused portion of the disability credit.

Not so. All households whose children are certified as eligible under the conditions of the disability tax credit can transfer the unused portion of the credit on behalf of their child with little or no income. But a reading of the General Income Tax and Benefit Guide does not make this eligibility immediately obvious.

Moreover, many of the terms used in the tax provisions remain undefined or unclear. A health professional, such as a physician, must make a judgment as to whether a given individual is 'infirm' for the purpose of claiming the infirm dependant tax credit or the extended child care expense deduction. But there are no precise eligibility criteria with respect to the definition of 'infirm.'

In fact, there is only one thing clear about the current tax provisions for persons with disabilities: They are decidedly unclear. "Unfortunately, despite the importance of the interpretation of these terms, some are not clearly defined in the Income Tax Act or Regulations, and are explained in Revenue Canada publications in a very confusing manner (if they are explained at all)" [Beatty 1999: 71].

Another option is to consolidate all the information with respect to disability in one place in the General Income Tax and Benefit Guide – even if Ottawa chooses not to introduce a new disability tax credit. At the very least, persons with disabilities and their families would have a single place to go for information as to the appropriate claims. Simplifying the process would provide much-needed relief to many households which are not even aware that they are eligible for tax assistance.

The federal government should take immediate action to clarify both the individual terms and the requirements for eligibility for relevant tax provisions. It also should simplify the access to relevant provisions – possibly through a designated line on the tax form or one-stop 'window' for disability-related assistance. Persons with disabilities, along with parents whose children are disabled, should be consulted actively as part of this process.

Next steps

The so-called children's budget should take steps to simplify and clarify existing tax provisions. Households eligible to make a claim on behalf of children with disabilities should be able to understand their entitlement.

It is essential to ensure that families caring for children with disabilities receive financial assistance in recognition of their extra costs

for aids and equipment, specialized services and respite care.

Existing tax provisions suffer from the fact that they tend to have an institutional bias towards care (e.g., the medical expense credit and child care expense deduction). They also tend to be restrictive and exclusionary in their provision. The disability tax credit is based on a restrictive definition of disability. The medical expense tax credit allows a designated, but relatively narrow, list of eligible items. The infirm dependant tax credit and the caregiver tax credit employ limited definitions of age. Aside from the small supplement for working poor households permitted by the medical expense tax credit, the other relevant measures provide no assistance to households that pay little or no income tax. Yet they still must incur disability-related expenses.

Several changes can be introduced to make the income tax system more responsive to the needs of families that have children with disabilities. Major and immediate improvements could be made through enhancing the disability tax credit. This enhancement would involve easing the eligibility criteria, improving the value of the benefit and making it refundable. Alternatively, Ottawa could consider the introduction of a new refundable disability credit. It would move away from the institutional bias inherent in current tax provisions and allow an amount to be claimed in respect of the actual and hidden costs of disability.

Another possibility is to enhance the medical expense tax credit. It is the broadest tax measure in terms of its scope of allowable expenses. Improvements can be made with respect to the list of eligible items, the value of the credit in both absolute and relative terms, and its refundability.

Finally, the crucial area of services for families must be further developed. The Speech from the Throne stated that Ottawa will engage with the provinces "to increase resources and further strengthen supports for early childhood development" [Canada 1999: 6]. In Caledon's view, that promise requires the federal government to establish a national child development fund that will inject substantial resources into a wide range of supports and services for all families – including those with children who are disabled.

At the very least, even the 'fine words' in which current and future programs are ensconced must change. While well intentioned, the language of the new National Children's Agenda inadvertently can have the effect of leaving out or casting aside children with disabilities. These children already face far too many barriers to inclusion.

Endnote

1. The Canadian Association for Community Living makes this point in its Statement "Don't exclude our children: Include all Canada's children in the *National Children's Agenda*."

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